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Formation of a Support Group for Women with Multiple Sclerosis (MS) in the Inner-City of Buffalo

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Formation of a Support Group for Women with Multiple Sclerosis (MS) in the Inner-City of Buffalo

by

Shelaine Rigby

An Abstract of a Project
in
Creative Studies

Submitted in Partial Fulfillment
of the Requirements
for the Degree of

Master of Science

May 2009

Buffalo State College
State University of New York
Department of Creative Studies

ABSTRACT OF PROJECT

Formation of a Support Group for Women with Multiple Sclerosis (MS) in the Inner-City of Buffalo

This project details the design of a Multiple Sclerosis support group for women in the Inner-City of Buffalo. The author describes her plans to use her creative studies background, facilitation and leadership skills to impart knowledge to others like herself (women with MS), in hopes of increasing the quality of life they are currently experiencing by bringing them into contact with each other. This, in turn, will hopefully reduce isolation, feelings of loneliness and separation from friends and family.

_____

Signature

_____

Date

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Cynthia Burnett
Project Advisor

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DEDICATIONS

This project is dedicated to my family and one special friend but especially my nieces and nephews:

To Daria, Dajon, Devonna, Deron and Jaela:

Thank you for inspiring a new love for creativity in me. May you always have a zest for life and learning!

To my Mom, Brenda Johnson:

Thank you for supporting and encouraging me when I finally decided what I wanted to be when I grew up.

To Cicily and Jay:

Thanks for always having my back and being my voices of reason.

To Sam:

Thank you for being the best cheerleader/boy scout/facilitator/confidante a girl could ask for!

To Peggy:

Thank you for encouraging me all along in my academic and spiritual achievements.

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Thanks for being such a shining example and willing to listen to me all the time. You are missed.

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Thanks for all of your support, encouragement, great suggestions and help over the last 2-1/2 years!

All of my wonderful Paratransit drivers:

Thanks for getting me where I had to go safely, (even though you always brought me late on the last day of classes when I had a presentation)!

My MS support group members:

Thanks for coming and joining our group. I hope that we can continue to inspire one another as well as other persons with and without MS. I could not have done this without all of your assistance and willingness to share.

My wonderful classmates in the Creative Studies Department (especially Maisha, Ryan, Marybeth, Reba, Alyssa and Elissa, my sounding board partner):

Thank you for sharing all of your creative knowledge, thought-provoking questions and insights which caused me to “dig deeper” into myself.

Thank you for waiting with me after class on the nights we were dismissed early and for letting me vent as needed.

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Section One: Background to the Project

Purpose

The purpose of this project is to create a support group to help myself and others like me (women living with Multiple Sclerosis) find value, meaning and hope in our lives while helping others do the same for themselves after being diagnosed with this illness.

It was my desire to create a support group to assist women with Multiple Sclerosis to allow us to discuss with each other our challenges, concerns and most importantly to highlight our contributions. It is important to identify challenges and concerns because these are the issues that give us trouble and someone else may have dealt with these problems successfully and can suggest one or more solutions.

It is more important to highlight our contributions made so we so do not focus on the negative but rather the positive.

This interaction will show us that our lives as women with MS, though separate, are not necessarily very different and will be encouragement for us to persevere. Persevering is a large part of dealing with MS. Finding the courage and strength to continue another day is not always a given; for some, it is harder than others to find a reason to continue fighting against this constantly changing beast that saps strength, identity, confidence and pride (Thornton and Leo, 1992).

I decided to create a support group for women with Multiple Sclerosis because for the last few years I felt that some of the issues with MS were not

being discussed in a manner that was beneficial to me. According to Gordon et al., (2002),"the environment will either assist or prevent successful coping for the ill person".

The new women's self-help support group was formed because I had little success in locating a support group for women with Multiple Sclerosis in the city of Buffalo. Most of the support groups I heard or read about met in the suburbs which prior to having access to Paratransit was not feasible for me [Paratransit is an alternative mode of flexible passenger transportation that does not follow a fixed routes or schedules (http://en.wikipedia.org/wiki/Paratransit)].

I have had MS for over 16 years and sometimes felt misunderstood, isolated and invisible. Juraskova et al. verified in their study of 1145 Australians diagnosed with MS that "nearly 30% of participants lacked support from other persons with MS" (2008, what page?). I intend to do as much as possible to keep women with MS from feeling as I once did.

Looking back, I must admit that a lot of my isolation was of my own doing, since I felt like an oddball because I was 19 when I was diagnosed, just outside of the age range, 20-40, within which most diagnoses occur (Fursland, 2004, p.18). At that time, I was in college and had barely begun to live as an adult. To be diagnosed with MS at 19 was shocking and scary. At the time, I was somehow left me with more questions than answers.

After over one and a half decades of managing and dealing with the unexpected symptoms of Multiple Sclerosis, I feel extremely and uniquely prepared to share stories and anecdotes regarding my life with MS with others who may be new to this experience or are veterans like me and are still uncertain what their life will be like.

Rationale

Based on the facts that more women than men have this illness (Fursland, 2004; http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/index.aspx) and that Western New York has one of the highest rates of MS in the country (http://www.thejni.com/treatment_1b10.htm), I believe there is a need for this outlet in the city of Buffalo and am happy to provide this opportunity for women to talk with others who may have previously considered themselves to be disenfranchised, marginalized or left out of society. It is not unusual for a person with a physical disability to withdraw from society. Maneuvering between the sick and healthy worlds can be overwhelming, if not frustrating to say the least (Thornton and Lea, 1992). It is my hope to reconnect the disconnected and show them they are not alone.

Self-help support groups

Self-help support groups (SHSGs) are groups that are run by and for participants who share similar experiences (Dadich, 2007, p.422). I have been dreaming of beginning a self-help support group for MS patients for several years

and finally decided that there was no time like the present to pursue this worthwhile endeavor.

Benefits of SHSGs and how this project improves the quality of life for me and others

My dream was enlivened further when I read that "peer support activities have the potential to "promote authentic interactions between individuals that can enrich the life [of persons dealing with chronic illness] while providing a sense of purpose in the face of crisis (Gordon et al, 2002, p.172)." Gordon's statement mirrored my main reasons for beginning the self-help support group. Uccelli found peer support programs to be a common method of providing support for MS patients (p. 80). Uccelli also agreed with earlier studies of support groups of persons with chronic illnesses which found evidence of the support having an enabling effective result on the coping abilities of the participants. Members, in turn, became experts through sharing of experiential knowledge and seeking strategies for handling stress and identifying coping mechanisms.

Sheeley and Sullivan (2004), identified information, support and friendships as main benefits of support groups (p.50) while Thornton and Lea, (p.324) pointed out that these groups facilitate growths of confidence, pride, identity, trust, ability and sensitivity. Support groups are regarded as a key resource in dealing with a serious [or chronic] illness and positively affect coping while also offering "significant psychological benefit" (Meyerstein, p. 210).

The creation of this self-help support group improves the quality of life for women with MS by putting us in contact with each other. This action alone can alleviate the stress, pain and misery that is common to persons dealing with a physical disability (Livneh, Wilson and Pullo, 2004, p.1). The connection forged will be ongoing and life-giving, a result of the bond formed between the group members. In the early 1900's, Joseph Pratt, a Massachusetts General Hospital doctor noticed that group members were instrumental in positively affecting the emotional adjustments of other members to their illness (Livneh et al., p. 2).

How this project adds creatively to me and others

This project will help me gain greater confidence in my presentation and facilitation skills and allow me to impart knowledge to others to aid them in finding solutions for challenges for which a new eye might be needed.

Several of my general creativity skills - flexibility, originality and elaboration will be enriched through the design and growth of this group .

Flexibility will be increased because involving persons over whom I have little to no control may cause things to seem to go awry. If I just keep my composure and accept that I cannot always make things go the way I would like, then I will be okay.

I will need to review materials from prior creative problem solving classes to give good starting points for topics to bring up new, interesting and pertinent information for the group to discuss. Even in the midst of this, I must remain

flexible to allow others to suggest different topics or agenda items, thereby increasing the originality factor within the group.

Original ideas will be necessary to keep the group focused and involved. If the members are at least intrigued by my offerings then maybe they will want to come back next month. This is important to keep the momentum that was demonstrated at the first group meeting apparent at all subsequent gatherings. I am now toying with introducing icebreakers that will intrigue the members to clamor for more.

To get the group to go along with my wacky and unusual ideas, I will need to elaborate enough to get them on my side and to give them ownership in the solution (Torrance and Safter, p.113). I will be mindful of the great ideas that fell to the wayside because the details were not worked out.

It is clear that intrinsic motivation (Amabile, 1996) is apparent and high although it remained dormant for years. Amabile defined intrinsic motivation as the tendency to engage in tasks because one finds them interesting, challenging, involving and satisfying. As expressed earlier, I had visions of beginning the support group for several years. I did not move forward because I was unsure of how to get it started. Unbeknownst to me, all that was needed was a little effort, some originality, desire and a plan.

Facilitation skills learned will need to be identified and drawn on to prepare me to begin and lead the group. The skills I recognize as being part of my facilitator's tool kit are:

1. *Communication skills – being able to effectively communicate my plans to the group and assisting group members in doing the same.*
2. *Group management skills- effectively managing information flow within the group and ensuring energy is high and members are committed to achieving identified goal(s), checking non-verbal cues are matching verbal language.*
3. *Preparation skills-producing resources for group members, agenda prepared prior to meeting, using space appropriately, pacing meeting and objectives efficiently, and using tools effectively.*
4. *Presentation skills – producing, distributing and discussing agenda items at start of meeting, explaining tools to be used in clear manner and answering questions, speaking clearly and authoritatively when giving examples of tools being used (*Miller, Vehar and Firestien, 2001, p. 6*).*

Leadership skills

I am using influence to begin this group and to spread the word about it to nearly everyone I know.

Tools of creativity will be used to enrich the group experience. The result should be learning the use of a tool they have not used before which will directly increase their knowledge base and may pique their interest in the study of creativity.

Section Two: Pertinent Literature

Introduction

I was pleasantly surprised to discover that a wealth of research and information on support groups, support programs, self-help groups and facilitation of these groups exists. Authors seemed to generally agree that change was needed to make these groups more effective but rarely agreed how best to accomplish the change.

It was quite reassuring to recall that I possess a large quantity of books that described best practices for facilitating groups. I often perused pages of long ago with fondness when remembering where and when I first used these books. Taking the time to delve deeper allowed me to discover more of the book that had gone unused but now was beneficial to my purpose at hand.

Pertinent Elaboration

Multiple Sclerosis – What is it?

"Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system (CNS), which is made up of the brain, spinal cord, and optic nerves. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. The progress, severity, and specific symptoms of MS are unpredictable and vary from one person to another" (http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/index.aspx).

Uccelli et al. (2004) described MS as an inflammatory demyelinating autoimmune disease of the central nervous system with which may come symptoms such as sensory impairment, extremity weakness, urinary dysfunction, visual impairment, fatigue, spasticity and in-coordination. Schwartz similarly characterized Multiple Sclerosis as a chronic, demyelinating disease which can affect one's vision, sensation, ambulation, bladder bowel control as well as coordination.

Both authors agreed that managing any number of the previously noted difficulties could lead to significant strain on family members which in turn could result in a decrease of social support, employment and ability to fulfill family and social roles (Schwartz, p.211; Uccelli, p. 80).

Types of MS

At diagnosis, MS may appear as relapsing-remitting for one decade or longer, and later its course can transform into one of the progressive types. This is just one part of the uncertainty, variability and insidiousness of this illness:

- **Relapsing-remitting MS:** characterized by unpredictable acute attacks, called "exacerbations," with worsening of symptoms followed by full, partial or no recovery of some function. These attacks appear to evolve over several days to weeks. Recovery from an attack takes weeks sometimes months. The disease does not worsen in the periods between the attacks. This pattern usually occurs early in the course of MS in most people.
- **Primary-progressive MS:** characterized by a gradual but steady progression of disability, without any obvious relapses and remissions. This form of disease occurs in just 15% of all people with MS, but it is the most common type of MS in people who develop the disease after the age of 40.
- **Secondary-progressive MS:** initially begins with a relapsing-remitting course, but later evolves into progressive disease. The progressive part of the disease may begin shortly after the onset of MS, or it may occur years or decades later.
- **Progressive-relapsing MS:** This is the least common form of the disease and is characterized by a steady progression in disability with acute attacks that may or may not be followed by some recovery. People with progressive relapsing MS initially appear to have primary progressive MS (http://www.webmd.com/multiple-sclerosis/guide/how-disease-progresses).

Approximately 400,000 Americans have MS, and every week about 200 people are diagnosed (http://www.nationalmssociety.org/about-multiple-sclerosis/FAQs-about-MS/index.aspx#howmany). Western New York has one of the highest prevalence rates of MS in the United States (http://www.thejni.com/treatment_1b10.htm). Since MS is significantly more common (at least 2-3 times) in women than men (http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/index.aspx) and because the unpredictable physical and emotional effects of the disease continue throughout a person's life (http://www.webmd.com/multiple-sclerosis/guide/how-disease-progresses).

My main learning from the articles referenced in my paper was how very new (Livneh et al., 2004) and helpful support groups are and have come to be. They can be found for any disorder, disease or condition and may not be used by one particular group of sufferers and could be open to all.

Self-help and peer-to-peer support groups are different from support groups because the former are run by and for persons who join together on the basis of common experience(s) (Dadich, 2007) to help one another and the latter is run by professionals or para-professionals (Sheeley and Sullivan, 2004, p. 53).

Benefits of support groups are listed as information, support, friendship and easing of anxiety regarding transitioning into the able-bodied community (Livneh et al., 2004) and between the sick and healthy worlds (Thornton and Lea, 1992). Sheeley and Sullivan (2004) noted that self-help groups give comfort and

encouragement by allowing members to see that others are living well with MS (p.53).

Courts et al., (2005) found that women (wives of MS patients) involved in her study seem to need more of an emotional contact. They desire to be asked about how they are doing, to be heard, as well as receive a thoughtful response from the listener that ensures she was heard.

Schwartz (1999) was of the statistical belief that teaching coping skills was more beneficial for improving the quality of life for MS patients than peer-support. Uccelli et al., 2004, suggested that more skills-based training was needed and Courts et al.(2004) asserted that spouses needed to be included in managing the illness as well as receiving advocacy skills. Also suggested by the participants was more training for the public about the invisible symptoms of MS (fatigue cognitive deficits, etc.) and Thornton and Lea, 1992 disclosed that groups give a "powerful sense of identity control over the illness(p.324)" . The authors further discuss the groups effect facilitating increases in "confidence, trust, self-valuing, pride, responsibility, ability, knowledge, sensitivity to others and development of a collective voice (p. 324)".

Juraskova et al.,(2008) revealed that close to 30% of MS patients in their study were lacking support from others with MS. Particularly interesting to me was Juraskova's (2008) finding that burnout in facilitators was identified as most often proceeded by lack of contact with other facilitators (71%), idleness within

the group (50%) and the membership not growing (41%). These factors intrigued me and warned me to be watchful for any and all as our group progresses.

Gordon and colleagues (2002) reviewed the ways in which 40 women coped with their chronic illnesses (lupus, MS, osteoporosis, rheumatoid arthritis and others with a combination of the aforementioned four). Ages were between 28 and 79 and all were specifically asked about the "role religion played in their experiences and the way they made meaning in their lives or coped with their illness (p. 162)". The majority who were successfully coping identified religious beliefs as a source from which they received strength. Counselors were advised to be aware of their own religious beliefs and assist clients in redefining meaning in their lives. It was further suggested that prayer, meditation, silence and reminiscing may be strong sources for coping.

Meyerstein (2005), too, noted that support groups positively affect coping and the course of the illness. Commenting on Moran's 2002 study, Meyerstein confirmed the existence of a "significant psychological benefit " added by support groups to their participants' quality of life. A spiritual perspective is introduced through a suggested healing time and space formed as a result of inspiration, comfort, connection and support (p. 207).

A cheerful re-visit of the thinking skills model of creative problem solving (CPS) occurred by re-examining the process used to decide, determine and define the group, its scope, membership and introduction. Puccio et al. (2007),

provided the necessary guidance by assisting my exploration of the thinking skills – diagnostic, vision, strategic, evaluative, contextual and tactical.

Selected Bibliography

Chien, W., Chan, S., Morrissey, J., & Thompson, D. (2005). Effectiveness of a mutual support group for families of patients with schizophrenia. *Journal of Advanced Nursing*, *51*(6), 595-608. Retrieved April 28, 2009, from CINAHL Plus with Full Text database. Clare, A. (1990). The psychological aspects of disability, paper presented to the *Annual Conference and Scientific Symptoms of the International Federation of Multiple Sclerosis Societies,* Dublin, Ireland.

Dadich, A. (2009). Researching community-based support networks: What policymakers should know. *Journal of Community Psychology*, *37*(2), 194-210. Retrieved February 17, 2009, doi:10.1002/jcop.20288.

De Simone, P. (1989).Demoralization in multiple sclerosis. *MS Quarterly Report, 8(4),p. 48-9.*

Drulovic, J., Riise, T., Nortvedt, M., Pekmezovic, T., & Manigoda, M. (2008). Self-related physical health predicts change in disability in multiple sclerosis. *Multiple Sclerosis (13524585)*, *14*(7), 999-1002. Retrieved April 28, 2009, doi:10.1177/1352458508088917

Elfline, J. (2008, Fall2008). Exploring a Second Life. *Momentum (19403410)*, *1*(4), 51-51. Retrieved April 27, 2009, from Academic Search Premier database.

King, M. (2004). Help from Self-Help Groups. *Inside MS*, *22*(2), 7-7. Retrieved April 27, 2009, from Academic Search Premier database.

Making Strides newsletter http://www.making-strides.net/ Malcomson, K., Lowe-Strong, A., & Dunwoody, L. (2008). What can we learn from the personal insights of individuals living and coping with Multiple Sclerosis? *Disability & Rehabilitation*, *30*(9), 662-674. Retrieved April 27, 2009, doi:10.1080/09638280701400730

Martinovich, R. (2001). A long road home. *Inside MS*, *19*(1), 64. Retrieved February 17, 2009, from Academic Search Premier database.

MS Connection: Quarterly Newsletter of Upstate New York Chapter of National Multiple Sclerosis Society. http://www.nationalmssociety.org/chapters/MOS/chapter-news/ms-connection/index.aspx

Mullins, L., Cote, M., Fuemmeler, B., Jean, V., Beatty, W., & Paul, R. (2001, May). Illness intrusiveness, uncertainty, and distress in individuals with multiple sclerosis. *Rehabilitation Psychology*, *46*(2), 139-153. Retrieved April 27, 2009, doi:10.1037/0090-5550.46.2.139

Multiple Sclerosis Association of America (MSAA) http://www.msassociation.org/

Multiple Sclerosis Foundation http://www.msfacts.org/

Neurology Now magazine http://www.neurologynow.com

Pickett-Schenk, S. (2002). Church-based support groups for African-American families coping with mental illness: Outreach and outcomes. *Psychiatric Rehabilitation Journal*, *26*(2), 173. Retrieved April 28, 2009, from Academic Search Premier database.

Schwartz, S.P. (1999). *300 Tips for making life with Multiple Sclerosis easier*. Demos Medical Publishing: New York.

Section Three: Process Plan

Introduction

Meetings I attended without an agenda or at least a clear purpose were disastrous and ridiculously long. I believed the agenda was important to keep everyone on task, and that became a very important part of my planning (Appendix E).

I knew I wanted to collect contact information on the members to make sure that we did not lose touch and designed a contact sheet to do so (Appendix F).

I needed feedback from the group on how well they believed the first meeting went so I could make changes we deemed necessary and gave each member an evaluation form to complete anonymously if she wished (Appendix D).

My process plan materialized very quickly after the completion of my initial timeline in my concept paper. The timeline came easy to me after I listed nearly every task imaginable related to this project. Mostly everything I needed to do was outlined in the timeline. The most difficult part was completing all necessary steps within the week I assigned them to myself. Thankfully, the original timeline was a work in progress and allowed me a bit of “wiggle room”.

It was very important to determine the order in which tasks needed to be completed. For example, I originally believed that I could request a space at my church for my group to meet before I received my pastor’s approval. His secretary was quick to relieve me of that misinformation and politely informed me that it was not possible but that she would be happy to help after approval was given.

After deciding what my project would be, my next step was to contact people who were familiar with support groups and their formation.

I contacted Di Hanny, organizer of the last MS support group I attended, and Pat Shulenburg, Program Coordinator for the Upstate New York Chapter of the National Multiple Sclerosis Society (NMSS).

I wanted the support group to meet at my church, St. John Baptist Church in Buffalo, NY. I needed to secure permission from my pastor, Dr. Michael Chapman. I sent a letter to my pastor and followed up with him a week later. Upon learning my request was granted, I immediately submitted a request for space at the church for my desired day and time. I chose Saturday, March 7,

2009 as the date for my first meeting because it was the only Saturday during MS awareness week. (I later learned that March is MS Awareness Month and it would have been apropos to hold the meeting anytime during March.)

Since I needed to advertise this event, I created a flyer to circulate to get the word out about my new support group. I left several copies of the flyer (which gave a synopsis of the purpose for the group as well as my contact information) at my church on the Sunday before my meeting. I told anyone and everyone about my plans and usually had a flyer ready to hand out.

I was pleasantly surprised that one support group member came because her husband saw the flyer on Buffalo TV Billboard. I was shocked that it actually was aired because I took a shot in the dark and faxed the flyer to them. Later, I learned that information is supposed to be received 4 weeks before the event and it will be displayed 2 weeks before the event. So, it is a mystery to me how my flyer that was sent only 5 days before the event ever made it on screen.

I knew of three (3) other women with MS and reached out to each by personally inviting them to attend my inaugural meeting. I encouraged them to share information about the meeting with anyone they knew who might be interested or affected.

My next task was to determine what would be my agenda for the meeting. I was so nervous that I had difficulty focusing and creating the agenda. When I asked my project class for assistance, it turned out that my flyer pointed to what the agenda should be. Once the agenda was off my to-do list, I moved on to

deciding which light refreshments would be served. I intended to serve pizza and wings but was concerned about how much food to order since I neglected to arrange for people to RSVP with me.

I planned for 5-10 persons to attend and decided on the menu significantly. I listened to a suggestion from a co-worker and decided to purchase breakfast/brunch food instead of lunch.

I admit that I was very nervous when the room I reserved only c0ntained myself at 12:15 pm. Thoughts were racing through my head: “I can’t believe that no one showed up”, I” built it but they didn’t come”, “Maybe I was wrong, I am the only person with MS in Buffalo who feels disenfranchised, overlooked and invisible.”

Luckily the first person came at 12:20 and another called by 12:30, she was on her way with her mother. I started to feel much better and by 1:00 we had a total of 6 persons at the meeting, 5 of which had MS. We spent most of that session dialoguing and sharing information about our lives with MS and what we each do to manage this illness.

I learned that we were all at different stages with the MS. I am the only member currently working (and attending graduate school). I have the earliest diagnosis and am the youngest thus far.

My final hope is that the group will continue to grow to the extent that we can no longer be ignored and leave a lasting positive impression on all who interact with us.

Project Final Timeline

Date	Action	Time required
January 27-31	Collect and review potential resources	3 hours
January 28	CRS 690 - Project class	3 hours
February 1-7	Contact Di Hanny, organizer of other MS support group	1 hour
February 4	CRS 690 - Project class	3 hours
February 8-14	Email maker of Copaxone to request 10-15 copies of Multiple Sclerosis Handbook	5 minutes
	Send letter to Pastor Chapman notifying him of my intention to begin MS support group	1 hour
	Request space for 15 at church on Saturday, March 7, 2009	30 minutes
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
February 15-21	Research Buffalo Billboard and find out how to get my meeting posted	30 minutes
	Speak with Stephanie Ball, potential member, to discuss other possible	1 hour

	group members	
	Distribute /send out flyers to local neurology clinics (Baird MS clinic, Jacobs Neurological Institute, Degraff Memorial Hospital, Dent Neurological)	2 hours
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
February 22-28	Draft feedback forms and contact sheet for group members and myself	1 hour
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
March 1	Talk with potential members about interest in group and first meeting	1 hour
March 1-7	Shop for muffins, croissants fruit and water	40 minutes
	Bring nametags, markers, feedback & contact forms for meeting	30 minutes
	Poll group members for best day and time for next monthly meeting	15 minutes
	Email/meet/talk with sounding board partner re: status of our projects	1 hour

March 4	CRS 690 - Project class -	3 hours
March 8-14	Review 3/7/09 group meeting and complete PPPCo	45 minutes
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
March 15-21	Submit request for room at St. John Baptist Church for April and May meetings	10 minutes
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
March 22-28	Call/email group members to remind them about April 2009 meeting	1 hour
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
March 27	Project draft work	8 hours
March 29- April 4	Prepare agenda for April meeting	30 minutes
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
April 1	CRS 690- Project class	3 hours

April 3	Project revision work	5 hours
April 5-11	Complete PPPCo for April meeting. Review feedback forms from group.	1 hour
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
April 6	Project revision work	4 hours
April 8	CRS 690- Project class	3 hours
April 12-18	Collect items for May meeting	3 hours
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
April 19-25	Submit request for space- May meeting	1 hour
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
April 20	Project revision work	8 hours
April 26	Project revision work	8 hours
April 26 – May 2	Shopping for food for May meeting	1 hour
	Bring nametags, markers, feedback & contact forms for meeting	30 minutes
	Prepare agenda for May meeting	1 hour
	Prepare icebreaker for	2 hours

	May meeting	
	Email/meet/talk with sounding board partner re: status of our projects	1 hour
	Finalize revisions on project/ review before handing in	8 hours
April 27	Project revision work	8 hours
May 3-9	Complete PPPCo for May meeting. Review feedback forms from group.	1 hour
May 6	CRS 690 – project class	3 hours
May 13	CRS 690 – Project class	3 hours
Total Hours		108 hours and 5 minutes

Section Four: Outcomes

Introduction

The newly –formed, women only support group took off with a "bang" and left me with a fleeting sense of success. It would not be long before I received a true test of my fortitude needed to keep the group on track. I also began to understand some of the frustrations of facilitators described by Juraskova (2008).

There were several outcomes which resulted from the creation of the MS support group for women:

1. the new support group of 6 women, 5 with MS,

2. a heightened awareness of resources for persons with Multiple Sclerosis,
3. a greater understanding of the stipulations involved in setting up a support group under the auspices of the National Multiple Sclerosis Society (NMSS),
4. greater confidence in my ability to facilitate groups and
5. appreciation of the amount of planning and organization necessary to create and run such a group.

The new support group for women with MS is the most significant outcome because it is being described by one member as “this is support”. It is beneficial for me as well since it gives me an opportunity to practice and share my craft of creativity and learning with group members

Section Five: Key Learnings

Introduction

My key learnings ranged from embracing newly discovered data to revisiting old knowledge, and involved taking a closer look at resources I previously possessed and using them another way.

The main key learnings I received were:

1. How to design and create a support group from the ground up.
2. Gaining a greater understanding of what is needed by female MS patients.
3. It is okay if everything does not go as planned.

Designing and communicating the information about the creation of a new support group was much easier than I thought it would be, and did not entail all the vehicles I originally planned.

I intended to use the local MS clinics to get the word out about my newly designed support group, but as time and limitations dictated, the flyers were never sent. They were, however, shared with and given to friends, relatives and church members. All of these persons were asked on the flyer to “tell women with MS about this group. Encourage her to come and share how she is handling life after diagnosis.”

I was familiar with Buffalo TV Billboard and had previously seen events displayed briefly on Time Warner Cable Channel 21. A quick search on the City of Buffalo website proved most useful in locating information on use of that “free publicity” channel. One of the members said that she came because her husband saw the announcement on the Buffalo TVBillboard.

Initially, I thought that partnering with the local chapter of the National Multiple Sclerosis Society (NMSS) was the best and most logical way to begin but after reading the NMSS manual entitled *Facilitating Self-Help Groups: A Manual for Self-Help Group Leaders (2008)*, the 69 page document left me rather disappointed and unimpressed with all of the signs of allegiance and binding conditions necessary to receive funding from the NMSS.

I immediately shifted my plans and decided to begin this group on my own terms with no assistance, financial or otherwise, from that organization. I was so

excited by this time and had touted my new group to so many others that I knew there would be no turning back now. So, with the proceeds of my recently received federal tax return, I endeavored to purchase enough food for at least 10 group members (my high end of hope).

I gained a new appreciation for media with which I was flooded monthly or quarterly. It was in these materials that I could read about others like myself and my group members to share stories culled from the pages of Momentum and MS Focus. It was within those pages that I received my greatest hope to walk more normally and less Frankenstein-like and possibly without assistive devices.

A fuller understanding of the reason for the National Multiple Sclerosis Society's (NMSS) existence occurred to me after reading its *Facilitators Self-Help Groups: A Manual for Self-Help Group Leaders (2008)* which was sent to me by Pat Shulenberg, Program Coordinator for the WNY chapter of the NMSS. Although I was repelled more than intrigued by the information contained therein, I respect the stance and view of the NMSS on its policies for new groups.

Unexpected benefits were revealed to me as I completed my Pluses, Potentials, Concerns and overcoming concerns (PPCo). I was happy to point out what was good, what could have been done better, and what should be removed altogether. It did take a considerable bit more time to overcome the concerns generated but it was all worthwhile since I now had a great game plan for tackling my second and third meetings.

A new recognition that my previous self-imposed label of “organizationally-challenged” may not have been accurate since I was able to successfully plan and implement my plan almost effortlessly. It was surprising when everything came together because I had been claiming and believing that my ability to organize was seriously impaired (either from birth or since MS remains undecided).

I had conveniently forgotten that in college, with no prior experience, I ran the backstage of a fashion show without incident which included 20+ models, wardrobe changes galore and necessitated elaborate planning to ensure the models had enough time to change attire between scenes.

Content

Things that worked in the overall project – why and how

Starting the support group required much less than I imagined all these years when I originally envisioned this group beginning. But it did require much reading and digesting of information regarding support groups in general and their purposes. It also required speaking with persons who were knowledgeable about this to receive a first-hand account of their experience including their challenges to avoid my being blindsided by these same obstacles and issues.

It was encouraging to learn that peer support groups are believed to be effective and are considered inexpensive (Uccelli et al., 2004).

It was equally discouraging to read that patients who have better mental health functioning may be at risk for deterioration in support groups (Uccelli et al, 2004).

Talking with all of the group members helped me learn that we shared a need to “talk with somebody who knows what we are dealing with and going through”.

Being the veteran MS sufferer of the group, I was surprised that these "newbies" had anything new about MS that they could share with me and could assist me in finding new resources for persons like us. I did learn about herbal supplements another member was aware of that may alleviate some unpleasant instances resulting from MS and cost significantly less than a doctor’s co-pay and the medicine prescribed to manage this particular symptom of Multiple Sclerosis.

Researching information for the group gave me reasons to read through my many magazines dedicated to people with MS. It was during a glance through one of these that I uncovered a relatively new device (neuro-muscular stimulator) that has existed for at least 4 years but that I had never heard of nor received information on from my neurologist.

As it would turn out after being evaluated by a professional, I learned that I am not a candidate for this device because my weakness is not in my ankle (for which it is designed) but in my left quadriceps or thigh muscle. As a result of my due diligence, I am able to share my experience and the flow of the process from initial interest to evaluation for this apparatus.

Things to change or do differently in the overall project – why and how?

After facilitating three (3) meetings, it has become painfully clear that agendas are not working with this group. I now plan to abandon my original belief that an agenda will keep us on task. This group desires a great deal of interaction which mostly consists of talking face to face. In lieu of teaching tools, I may need to consider fun and interactive icebreakers to serve this group best.

My menus have become mundane and expected. It would not hurt to try something different next month. Maybe a relish tray will be served rather than fruit.

The group is not solid yet because few of the original members have returned more than once. This may require me contacting all members directly by phone and by email to ensure a crowd of at least six (6).

Process

Although the first meeting was mostly a getting -to-know-you affair with little time for teaching, the late arrival of most members necessitated a departure from my original agenda, I was able to draw on my creative teaching and "be flexible" with this previously unchartered territory within this group as it was forming. Embracing ambiguity is still a bit scary to me, so the best way for me to get there will be through baby steps.

Approaching the group from this vein allowed me to "look at it another way". It turned on my stretching abilities and caused me to go into meditation

mode which involved silently repeating loving kindness to myself and all of the group members. This is new for me and worked in alleviating tenseness and stress I was feeling because things were not going as originally planned.

My awareness of the number of available resources has definitely changed since my initial diagnosis nearly 17 years ago and most notably within the last 4 months. I failed to research the existing information since I believed that it was limited based on prior experience and did not bother to revisit it at that time since my initial impression was unfavorable.

This project gave me a reason to avail myself of all the data that I was receiving several times a year but was making little time to review. This media went untouched because my view of it was never modified. Once I opened my mind to the possibility that there was useful information in these magazines and on their web sites, I actually found uses for these sources.

I gained a desire to explore and uncover what proved to be useful data after my project topic was decided and finalized. Wanting to be considered an expert on Multiple Sclerosis, I was quick to collect and review information from magazines about which I previously was aware. Some of the resources I re-discovered were *Momentum – the magazine of the National Multiple Sclerosis Society, Neurology Now, and MS Focus – magazine of the Multiple Sclerosis Foundation.*

Momentum proved to be useful because it includes articles relevant to persons with MS. The font is larger than usual to make it easier for persons who may have difficulty seeing or reading small print.

Neurology Now is a pertinent source as it talks not only about Multiple Sclerosis but about many neurological disorders such as Parkinson's disease, Migraine headaches and Epilepsy giving its readers a full spectrum of neuroscientific information and current perspectives on each disorder. It is published 6 times a year.

MS Focus is another magazine that like the others is free and available online. The Multiple Sclerosis Foundation is based in Fort Lauderdale, Florida and offers its quarterly magazine in audio format also.

What I also gained was additional knowledge from group members who were all willing to share stories of experiences, whether good or bad. Since many of the reflections shared were from formerly employed persons, these persons were willing or needed to share about an injustice which resulted from a perception of her MS based on false data or fear.

I was initially very excited about the prospect of creating a new support group especially under the guidance of the National Multiple Sclerosis Society. The preliminary euphoria was quite brief. It was a short time later after reading their *Facilitating Self-Help Groups: A Manual for Self-Help Group Leaders (2008)* that I returned to reality. I found this manual and its standards restrictive and

overwhelming. Reaching this conclusion after reading that “Individuals who serve as self-help group facilitators should possess skills and attributes [such as]:

- Willingness to learn about and promote National MS Society programs and events
- Engagement in, or support of, chapter-wide activities (e.g.MS Walk, advocacy, etc.)
- Chapters will offer, and all active self-help group leaders will participate in, structured orientation and on-going opportunities. (New leaders are expected to participate and complete a NMSS training designed for new group leaders (p. 8))
- Religious Issues: Society policy allows for groups to have a specific faith based focus, as long as a more generic group is offered within reasonable proximity.
    - Faith is an important coping mechanism for many people living with MS. However, the National MS Society is a secular organization, welcoming those of every faith, and those who espouse none. In general, we ask that our groups do not include prayer as part of their formal meeting. By doing so the group runs the risk of alienating and/or excluding some group members, which is in direct conflict with the guideline pertaining to open membership (p.13).

I was most concerned with the last statement from the manual because I had received approval for the meetings to be held at my church monthly. I was

sure that at least one if not more group members would want to pray at some point in our church and might be offended if I quoted them chapter and verse from the manual about being prohibited by the NMSS. It seemed that the authors of the manual disagreed with Gordon's assessment that "religious beliefs are important in coping with chronic illness (2002)." It was with these considerations resulting from the NMSS stipulations that I decided to build this group without their financial assistance or publicity.

Preparing for the first meeting had me on "pins and needles". I was a basket case because I was unsure how to approach the group and also nervous about how I might be perceived by the members. To add to my uncertainty and fear, I was purchasing refreshments for an unknown number and just prayed that I had enough and would not need a miracle like the one Jesus performed at the wedding at Cana with the two fishes and five loaves of bread (King James Version, John 2:1-11).

I impressed myself with the amount of foresight and planning I used (a talent for which I am *not* usually known). There were five forms and a letter created to begin this support group.

I prepared a letter to my pastor (Appendix B) requesting the church to be the site where our monthly meetings took place. I prepared the feedback forms (Appendix D) for attendees by altering feedback forms from previous activities I conducted and made these specific to this meeting. I created a sign-in sheet (Appendix G) as well as a contact sheet (Appendix F) for all group members to

complete. I also made copies of the monthly flyer (Appendix C) for members to share with anyone they believed might be interested and /or affected by MS. All of the forms were given to members in a folder with a pen. The group was very excited to receive these materials and to be able to leave with copies of all the information created for them.

I recognized that I used leadership abilities (Mumford, 2000) as well as thinking skills to make this group a reality. Mumford determined that "leaders must not only exercise influence, they must decide when, where and how influence will be exercised to bring about the attainment of social goals."

Visionary thinking was at work all along. I had to be able to see the support group before I could plan how it would start and develop. I needed to ask myself "where do I want to go?" (Puccio, Murdock and Mance, 2007, p. 54). My answer to that question told me what needed to be planned and how to plan for the making of the group.

Strategic and contextual thinking were involved as I moved toward my goal and identified gaps, hindrances and possible impediments to my success (Puccio et al., p. 55-58). This type of thinking was used when I determined that my group might be more well-rounded without assistance from the local chapter of the National Multiple Sclerosis Society.

Evaluative thinking was needed to review the meetings through the eyes of the participants and myself. Constructing tools necessary to receive this information was apart of the process. Also involved was ideational thinking

(Puccio et al., p. 56) as I needed to determine which questions should be asked to get the desired information.

Tactical thinking abounded in the process to getting my group going. As I noted below, I made a detailed listing of each and every step that needed to be taken to get the group started and ready for presenting to the potential members. Tactical thinking was used to formulate a plan with specific and measurable goals (Puccio et al., p. 59). It was merely a wish and a potential plan back in January and only 2 months later, our first meeting was being held. At the meeting, I distributed evaluation forms and collected contact information from the participants.

I began by identifying what needed to be done and set out on accomplishing the tasks as soon as possible. I had no real idea what to do to start this group and that is what kept me at bay for the last 7 years or so. I was afraid to fail, so I never tried. Not until it came down to whether or not I would complete my Master's degree. When it was that important and real, everything just came together. I started out by writing down all the things I knew I needed to do to get going such as securing a location to meet, deciding on the date and time for the first meeting and learning what happens at support group meetings.

To accomplish the first goal, I knew that I needed to contact my pastor and receive his approval before I could do anything else. So I drafted a letter to him explaining what I intended to do and why. I faxed that to him right away.

At the same time, I put out a feeler to the local chapter of the National Multiple Sclerosis Society (NMSS) to see if they could send me any information about support groups. I left my name and number for a representative to follow up with me. The following day I received a call from the program coordinator for the Western New York chapter of the NMSS and she said that she would help me publicize my group and send me material to read.

One major component to my support group was securing a location to meet. The only place I ever imagined the group meeting was at my church, so I began by drafting a letter to my pastor to receive his approval.

I followed up by calling my pastor after not hearing anything for a week. I learned from the secretary that my proposal had been approved and I was off and running.

Once that was completed, I knew I needed to request a space on a particular day for a specific amount of time. I followed up by drafting a flyer by using Microsoft Publisher, software with which I was unfamiliar. Due to it being a member of the suite of Microsoft Office and my being familiar with Microsoft Word and Excel, it was very easy to use.

I planned a menu early on that was most convenient for me - pizza and wings. As the date came closer, a suggestion by co-worker changed all my plans and caused me to actually shop for the meeting and consider the health of the participants. In doing so, I opted for fruit, muffins, cocktail croissants and water. A much healthier choice than my original menu. It took a bit more effort but I felt

better about the choice made because it was done with true concern and thoughtfulness as the only motives.

Section Six: Conclusion

Introduction

I was correct about this support group being necessary to this area where it is located and was founded. I endeavored to build it, and they did come. They came to support one another and to support me.

I had no idea that setting up a support group was so logical and took only a little time, consideration and planning. None of these steps were as monumental as I previously imagined.

I was unaware how prepared I was to lead after taking a course on creative leadership. From that course, I was able to write a vision for the group and it made my goal very real and easily explainable (in case I need to give an elevator speech about it one day).

The hardest part for me now is remaining as excited and energetic as I was before I started the group. That amount of involvement and attention to detail is still necessary to keep the members rallied and invested. This need may demand that I find more willing assistants or co-facilitators.

The costs were rather low for the light refreshments I offered at each meeting. Even the folders and pens I gave away were of inconsequential

monetarily for what I received in return: increased self-esteem and valuable practice with my creative skills.

I seriously underestimated myself as well as the potential within me to complete my mission of beginning a support group for women in Buffalo, New York.

Reflecting on the last two and one half years in the Creative Studies department at Buffalo State College, I realize that my goals, though lofty, came into focus, became more achievable and were brought into reach, as a result of the education received in this program.

Next Steps

Introduction

My next steps are focused on how to make the group better and taking what I learned from this experience and sharing with others. The planned steps have a theme of inclusion and will not be taken unless the membership is in agreement with each one.

What I see myself doing now is:

- Inviting speakers to talk to the group.
- Planning to speak with other groups about MS.
- Continuing the group through the summer, if agreed by group.
- Considering and developing ways to expand the group.
- Requesting more input from group members.

- Requesting a volunteer to co-facilitate.

Inviting speakers to talk to the group

My plan for inviting speakers is admittedly underdeveloped because I have not brought this up for discussion in the meeting yet. I have had one author/professor offer to speak with the group regarding health concerns. I would like to speak with the group to get an idea of what avenues they might like to pursue before moving forward.

Planning to speak with other groups about MS

I recently received an invitation to speak with another support group for persons battling Sarcoidosis. Sarcoidosis is a disease characterized by the development and growth of tiny clumps of inflammatory cells in different areas of your body. Sarcoidosis can affect virtually any organ, but most commonly it affects your lungs, lymph nodes, eyes and skin. (http://www.mayoclinic.com/health/sarcoidosis/DS00251).

I am honored to have been offered to have an opportunity to speak to persons with a condition that shares side effects with Multiple Sclerosis. I hope to gain a greater understanding of Sarcoidosis as well as imparting knowledge to this group about MS. I am hopeful that the result will help increase the number in the new network I am helping to form.

Continuing the group through the summer

Although I would like to continue the group through the summer, I am aware that most persons with MS find the summer extremely challenging and may not wish to be sapped of strength during that season, and may decline. If this is the decision by the group as a whole, I will follow their suggestion and place the group on hiatus for the summer.

However, if the group decides to meet during the summer months, the time of the meeting will most likely be adjusted to accommodate this plan.

Currently, the time for the meeting is at 12 noon to allow the members time to rest before coming to the session. In the summer, the sun is at its peak at its peak at noon and a different start time will need to be arranged.

Considering and developing ways to expand the group

I will hold a brainstorming session to gather ideas from others for ways to expand the group. This topic is of importance to me as difficulty in recruiting new group members was noted as significant in Juraskova's study of MS facilitators' challenges (2008). Also identified as a challenge was stagnation within the group.

I am aware that there may be resistance initially as this is a part of the group forming process (Tuckman, 1965). The climate in the group is currently collegial but the addition of even one additional member could cause a change (reforming stage). I am willing to pursue this direction because I wish for no woman to be left without a life preserve while swimming in the choppy, shark-infested waters that are MS.

Requesting more input from group members

I realize the importance of this group and would love to incorporate ideas from the members into our future plans. As a near graduate of the Creative Studies department, I recognize the value in a lay persons' ideas and perspectives. I am very willing to give opportunities to willing persons and am hopeful that our group contains more than one. Sharing the responsibilities will take a load off of me and may even identify our next leader.

Requesting a volunteer to co-facilitate

Juraskova (2008) found that lacking a co-facilitator to be of concern for over 70% of responding surveyed facilitators. I am hoping that identifying a willing participant at this time is early enough to alleviate much of the stress felt when only one person shoulders all of the responsibility.

References

Amabile, T. M. (1996). *Creativity in context*. Boulder, CO: Westview Press.

Courts, N., Newton, A. and McNeal, L. (2005). Husbands and wives living with Multiple Sclerosis. *Journal of Neuroscience Nursing, 37*(1), 20-27.

Dadich, A. (2007). Is Spirituality Important to Young People in Recovery? Insights from Participants of Self-Help Support Groups. *Southern Medical Journal*, *100*(4), 422-425. Retrieved April 28, 2009, from Academic Search Premier database.

Fursland, E. (2004). Completing the picture. *Nursing Standard*, *18*(22), 18-19. Retrieved February 17, 2009, from Academic Search Premier database.

Gordon, P., Feldman, D., Crose, R., Schoen, E., Griffing, G., & Shankar, J. (2002). The Role of Religious Beliefs in Coping With Chronic Illness. *Counseling & Values*, *46*(3), 162-174. Retrieved April 27, 2009, from Academic Search Premier database.

Holy Bible (King James Version) Gospel of John 2:1-11.

Jacobs Neurological Institute. http://www.thejni.com/treatment_1b10.htm.

Juraskova, I., Chapman, J., Butow, P., Jolan, A., Zordan, R., Kirsten, L., et al. (2008). Challenges, needs, rewards, and psychological well-being of Multiple Sclerosis support-group facilitators. *International Journal of MS Care*, *10*(3), 85-93. Retrieved February 17, 2009, from CINAHL Plus with Full Text database.

Livneh, H., Wilson, L., & Pullo, R. (2004). Group Counseling for People With Physical Disabilities. *Focus on Exceptional Children*, *36*(6), 1-18. Retrieved April 28, 2009, from Academic Search Premier database.

Mayo Clinic http://www.mayoclinic.com/health/sarcoidosis/DS00251

Meyerstein, I. (2005). Sustaining our Spirits: Spiritual Study/Discussion Groups For Coping with Medical Illness. *Journal of Religion & Health*, *44*(2), 207-225. Retrieved April 28, 2009, doi:10.1007/s10943-005-2778-9

Miller, B., Vehar, J., and Firestien, R.(2001). *Facilitation: A door to creative leadership (3rd ed.)*.Williamsville, NY: Innovation Resources, Inc.

National Multiple Sclerosis Society. (2008).*Facilitating self-help groups: A manual* for self-help group leaders. National Multiple Sclerosis Society.

National Multiple Sclerosis Society. http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/index.aspx

National Multiple Sclerosis Society. http://www.nationalmssociety.org/about-multiple-sclerosis/FAQs-about-MS/index.aspx#howmany

Puccio, G., Murdock, M. and Mance, M, (2007). *Creative leadership: Skills that drive change.* Thousand Oaks, California: Sage Publications.

Schwartz, C. (1999). Teaching coping skills enhances quality of life more than peer support: Results of a randomized trial with multiple sclerosis patients. *Health Psychology*, *18*(3), 211-220. Retrieved February 17, 2009, doi:10.1037/0278-6133.18.3.211.

Sheeley, J., & Sullivan, G. (2004). With a little help from my friends. *Inside MS*, *22*(2), 50-53. Retrieved February 17, 2009, from Academic Search Premier database.

Thornton, H., & Lea, S. (1992). An Investigation into Needs of People Living with Multiple Sclerosis, and Their Families. *Disability, Handicap & Society*, *7*(4), 321-338. Retrieved April 27, 2009, from Academic Search Premier database.

Torrance, P. and Safter, T. (2007). *Making the creative leap beyond*. Hadley Massachusetts: Creative Education Foundation Press.

Tuckman, B. (1965). *Developmental sequence in small groups.* Psychological Bulletin, 63, 384-399.

Uccelli, M., Mohr, L., Battaglia, M., Zagami, P., & Mohr, D. (2004). Peer support groups in multiple sclerosis: current effectiveness and future directions.

Multiple Sclerosis (13524585), *10*(1), 80-84. Retrieved February 17, 2009, doi:10.1191/1352458504ms973oa.

WebMD. http://www.webmd.com/multiple-sclerosis/guide/how-disease-progresses.

Section Seven: Appendices

Appendix A : Concept Paper

Appendix B :Copy of my letter to my Pastor

Appendix C: Copy of flyer announcing new support group

Appendix D:Copy of feedback form distributed at meetings

Appendix E:Copy of first agenda

Appendix F: Copy of group contact sheet

Appendix G : Copy of sign-in (attendance) sheet

APPENDICES A-G

Appendix A

Title of Concept Paper: Formation of Multiple Sclerosis (MS) Support Group for Women in the Inner-City of Buffalo

Name: Shelaine Rigby **Date Submitted:** February 25, 2009

Project Type: **Use a Skill/Talent to Improve the Quality of Life for Others**

What is This Project About?

I will create a support group to help others like myself (women diagnosed with Multiple Sclerosis) find value and hope after being diagnosed with this illness.

Multiple Sclerosis can be debilitating and often leads to disability or impairment of limbs and or cognition. It can be difficult for a previously productive individual to make peace with sudden or severe changes resulting from the loss of capability whether it is physical or mental.

Since MS disproportionately affects women, it is my desire to create a support group to assist women living with Multiple Sclerosis so that they may discuss their fears and concerns, whether they are financial, social or personal.

Rationale for Choice:

Although I did find several support groups in the suburbs, I have not found this particular support group in the inner-city of Buffalo. I believe there is a need for this outlet and am happy to provide this opportunity for women to talk with others who may have previously considered themselves to be disenfranchised, marginalized or invisible to society at-large.

I have been dreaming of beginning a support group for MS patients for several years and finally decided that there is no time like the present to pursue this worthwhile endeavor. It should also be beneficial, if not at least uplifting, to those who do not believe or understand that there really is life after MS.

What Will be the Tangible Products or Outcomes?

An initial group of 5-10 people will attend 3 monthly meetings (March, April and May 2009) sharing information and personal experiences since contracting multiple sclerosis.

As a result of the formation of this group, the desired outcomes will include spin-offs (maybe for men) or duplication of this effort into social groups and networks that persons with MS can use as resources.

What Criteria Will You Use to Measure the Effectiveness of Your Achievement?

I will feel successful when I have formed a cohesive group of female MS sufferers who dialogue together and gain valuable information from one another.

I expect to gain or meet a new group of acquaintances as well as speakers. It is also my desire to speak with several groups that would like to learn more about disabled persons with MS and life after diagnosis.

Who Will Be Involved or Influenced; What Will Your Role Be?

Influenced and Involved

Female persons with MS, mostly in the Western New York area, will be involved in the beginning stages and hopefully influenced as well. If this group is successful, then it may be possible to form other groups to serve the needs of MS patients.

Influenced

Church members, members of the community, other support groups will be influenced when they recognize the challenges faced by these individuals and how they persevered.

Involved

My pastor, Rev. Dr. Michael Chapman, family and friends of women with MS, local neurologists and local neurology clinics will be involved in growing our membership and spreading word about the newly formed group.

My role initially will be to lead and engage the group in discussions. I will also facilitate the management of the group. This role can be shared with other willing participants.

When Will This Project Take Place?

This project will be the impetus for this group to come into existence. It is my vision that this will be ongoing longer than Spring 2009. The group should continue until it becomes obsolete, unnecessary or is no longer beneficial to its participants. Over time, it is possible that the initial purpose may evolve or change altogether, as determined by the membership.

It is designed to be a monthly discussion group and the first meeting is tentatively set for March 7, 2009. Additional meeting are planned for April 2009 and May 2009.

Where Will This Project Occur?

At St. John Baptist Church, 184 Goodell Street, Buffalo, NY 14204.

Why Is It Important to Do This?

This group will be important to me and MS patients because it will give all of us useful information as well as a safe forum to share concerns with other women who may have the same questions or similar experiences.

Additionally, efforts will be made to collect and share resource information with all interested persons.

Personal Learning Goals:

As a result of this project, I will:

- learn what is necessary to begin a support group from the ground up.
- gain a greater understanding of what is needed by other female MS patients.

How Do You Plan to Achieve Your Goals and Outcomes?

I will:

- spend a significant amount of time researching existing support groups and review their formation and benefits.
- encourage MS patients and their loved ones to believe that there is life after a diagnosis of MS.
- share and encourage the group to share personal coping skills and scenarios with the participants.
- assist persons with MS in realizing they have so much still to contribute. relate our struggle to biblical characters' struggle(s) which will hopefully encourage the group to continue in their fight against MS.
- share excerpts of Shelley Peterson Schwartz's "300 Tips for Making Life with Multiple Sclerosis Easier".
- distribute copies of the Multiple Sclerosis Handbook from Teva Neuroscience at the meetings.
- create a flyer announcing our first meeting on March 7, 2009 and distribute.

- contact the Local chapter of the National MS Society for information on MS support groups.

Evaluation:

- Formal evaluation will be written on feedback forms by members of the group.
- Informal evaluation will be given in response to a request for verbal responses.
- I will complete a PPCo after each meeting that will detail what worked, what didn't and what needs to be revised, discarded or added for future meetings.

Prepare Project Timeline:

Date	Action	Time required
January 27-31	Collect and review potential resources	3 hours
February 1-7	Contact Di Hanny, organizer of other MS support group	1 hour
February 8-14	Email maker of Copaxone to request 10-15 copies of Multiple Sclerosis Handbook	5 minutes
	Send letter to Pastor Chapman notifying him of my intention to begin MS support group	1 hour
	Request space for 15 at church on Saturday, March 7, 2009	30 minutes

February 15-21	Research Buffalo Billboard and find out how to get my meeting posted	1 hour
	Speak with Stephanie, potential member, to discuss other possible group members	1 hour
	Distribute /send out flyers to local neurology clinics (Baird MS clinic, Jacobs Neurological Institute, Degraff Memorial Hospital, Dent Neurological)	2 hours
February 22-28	Draft feedback forms and contact sheet for group members and myself	1 hour
	Price 2 large pizzas /party pizza for 3/7/09	1 hour
	Purchase name tags for meeting	1 hour
March 1-7	Order pizza for meeting	10 minutes
	Bring nametags, markers, feedback & contact forms for meeting	30 minutes
	Prepare icebreaker for meeting	2 hours
	Poll group members for best day and time for next monthly meeting	15 minutes
March 8-14	Review 3/7/09 group meeting and complete PPPC0	45 minutes
March 15-21	Submit request for room at St. John Baptist Church for April and May meetings	10 minutes
March 22-28	Call/email group members to remind them about April 2009 meeting. Encourage them to tell/invite a friend.	1 hour
March 29- April 4	Prepare agenda for April	30 minutes

	meeting	
April 5-11	Complete PPPCo for April meeting. Review feedback forms from group.	1 hour
April 12-18	Collect items for May meeting	3 hours
April 19-25	Submit notice for May meeting	1 hour
April 26 – May 2	Order food for May meeting	10 minutes
	Bring nametags, markers, feedback & contact forms for meeting	30 minutes
	Prepare agenda for May meeting	1 hour
	Prepare icebreaker for May meeting	2 hours
May 3-9	Complete PPPCo for May meeting. Review feedback forms from group.	2 hours

Identify Pertinent Literature or Resources:

Dadich, A. (2009). Researching community-based support networks: what policymakers should know. *Journal of Community Psychology*, *37*(2), 194-210. Retrieved February 17, 2009, doi:10.1002/jcop.20288.

Fursland, E. (2004). Completing the picture. *Nursing Standard*, *18*(22), 18-19. Retrieved February 17, 2009, from Academic Search Premier database.

Juraskova, I., Chapman, J., Butow, P., Jolan, A., Zordan, R., Kirsten, L., et al. (2008). Challenges, needs, rewards, and psychological well-being of multiple sclerosis support-group facilitators. *International Journal of MS Care*, *10*(3), 85-93. Retrieved February 17, 2009, from CINAHL Plus with Full Text database.

Making Strides newsletter http://www.making-strides.net/

Martinovich, R. (2001). A long road home. *Inside MS*, *19*(1), 64. Retrieved February 17, 2009, from Academic Search Premier database.

MS Connection: Quarterly Newsletter of Upstate New York Chapter of National Multiple Sclerosis Society. http://www.nationalmssociety.org/chapters/MOS/chapter-news/ms-connection/index.aspx

Multiple Sclerosis Association of America (MSAA) http://www.msassociation.org/

Multiple Sclerosis Foundation http://www.msfacts.org/

Neurology Now magazine http://www.neurologynow.com

Schwartz, C. (1999). Teaching coping skills enhances quality of life more than peer support: Results of a randomized trial with multiple sclerosis patients. *Health Psychology*, *18*(3), 211-220. Retrieved February 17, 2009, doi:10.1037/0278-6133.18.3.211.

Schwartz, S.P. (1999). *300 Tips for making life with Multiple Sclerosis easier*. Demos Medical Publishing: New York.

Sheeley, J., & Sullivan, G. (2004). With a little help from my friends. *Inside MS*, *22*(2), 50-53. Retrieved February 17, 2009, from Academic Search Premier database.

Uccelli, M., Mohr, L., Battaglia, M., Zagami, P., & Mohr, D. (2004). Peer support groups in multiple sclerosis: current effectiveness and future directions. *Multiple Sclerosis (13524585)*, *10*(1), 80-84. Retrieved February 17, 2009, doi:10.1191/1352458504ms973oa.

Appendix B: Copy of my letter to my Pastor

February 16, 2009

Pastor Michael Chapman
St. John Baptist Church
184 Goodell Street
Buffalo, NY 14204

Dear Pastor Chapman:

I am writing you to notify you of my intention to organize a new support group for women with multiple sclerosis (MS) in the inner-city of Buffalo.

Multiple sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. The progress, severity and specific symptoms of MS are unpredictable and vary from one person to another (http://www.nationalmssociety.org/about-multiple-sclerosis/whatis-ms/index.aspx).

I would like to hold monthly meetings at the church. The first one is tentatively scheduled for Saturday, March 7, 2009, time to be determined.

This endeavor is born out of my desire to organize an support group for multiple sclerosis patients and is becoming a reality because I have transferred that desire into my project which is necessary for me to complete my masters degree at Buffalo State College in May 2009.

It is my hope that you will grant my request as well as share this information with any persons that you are in contact with that could be useful or supportive as this group gets off the ground.

Please feel free to contact me at (716) 645-2532 between 8:30 am and 5:00 pm M-F, if you have any questions regarding this request.

Sincerely,

Shelaine Rigby

Appendix C: Flyer announcing new support group for women

New Multiple Sclerosis Support Group for Women

This new support group is designed to bring women with MS together to discuss our challenges, concerns and contributions.

Our next meeting is scheduled for:

Date: **Saturday, May 2, 2009**

Time: **12pm—2:00 pm** (light refreshments will be served)

Place**: St. John Baptist Church, 184 Goodell Street, Buffalo, NY 14204.**

If you know a woman with MS, please tell her about this group. Encourage her to come to share how she is handling life after diagnosis and find out how all of us manage this condition.

Appendix D: Copy of feedback form

Evaluation

Date: 5/2/2009

Name (optional): _____

What are you looking for in a support group?

_____

_____

_____

_____

_____

_____

Did this group meet your expectations? If yes, how so? If no, where did we miss the mark?

_____

_____

_____

_____

_____

_____

Suggestions for making this group better:

_____

_____

_____

_____

Appendix E: Copy of first agenda

AGENDA FOR MS SUPPORT GROUP MEETING

St. John Baptist Church – 184 Goodell Street- Buffalo, NY 14204

Saturday, March 7, 2009 - 12 pm – 1:30pm

- Attendance
- Purpose for group – Mine/Yours

- Mindful listening exercise
- What does support mean to you?
- Challenges
- Concerns
- What are you most proud about/of?
- Next meeting – Time and Date???

Contact Shelaine Rigby, Facilitator at:

(716) 885-3805 (home) or

(716) 573-0972 (cell)

Appendix F: Copy of group contact sheet

Contact List for Women's MS Support Group

3/7/09

Name	**Phone #**	**Email**
Shelaine Rigby	(716) 885-3805	rigby@buffalo.edu

Appendix G: Copy of Sign-in (Attendance) Sheet

3/7/09

ATTENDANCE - PLEASE SIGN BELOW

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____